Nurse-Led Supportive Care Intervention for patients with Advanced Liver Disease: Feasibility Study

Research Team:
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Background

• Mortality rates for Liver Disease up 400% since 1970
• 3rd commonest cause of premature death in UK
• Average age of death 59
• Erratic and unpredictable
• Liver transplantation unavailable for many

Patient experience

• High physical and emotional burden
• A lack of understanding and explanation of the illness
• No emotional support
• Poor continuity of care in health and social services
• Little or no anticipatory care planning or identification for a palliative care approach
Project overview

• **Project aim:** To test the feasibility of an intervention delivered by a supportive care liver nurse specialist to:
  
  – **Co-ordinate** care and improve quality of life
  – **Support** patients and carers
  – **Provide advice** to professionals in the community
  – Facilitate **anticipatory care planning**, through the use of KIS (Key Information Summary)

• **Evaluation** using mixed methods
The Study Population

• Patients with advanced liver disease

Inclusion criteria
• 1 or more unplanned admission due to decompensated cirrhosis
• Liver transplantation not appropriate

Exclusion criteria
• Expected survival <1 month
• Non-hepatic condition likely to cause death within 12 months
• Persistent cognitive impairment
## Recruitment

<table>
<thead>
<tr>
<th>Participants</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients recruited</td>
<td>47</td>
</tr>
<tr>
<td>M/F</td>
<td>31/16</td>
</tr>
<tr>
<td>Age</td>
<td>31-87 (mean 60.5)</td>
</tr>
<tr>
<td>Alcohol-related aetiology</td>
<td>31</td>
</tr>
<tr>
<td>Family carers</td>
<td>27</td>
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</tbody>
</table>
The Intervention

- “Thinking Ahead” booklet
- Face-to-face care review meeting
- Review letter to patient, GP and lead consultant
- Key Information Summary (KIS)
- Monthly follow-up calls for six months
- Final review letter and updated KIS to patient, GP and lead consultant
The role of supportive liver nurse specialist

• Act as case manager and co-ordinator
• Support patients and carers to live as well as possible
• Support care delivered by professionals in the community
Outcomes

• Supportive care liver nurse role, specialist advice and continuity of care welcomed by all
• Intervention and methods of evaluation feasible and acceptable
• Improved care experience
• Some reduced amount of contact with GPs
• 85% of participating patients had a KIS created or updated.
• Information gained will guide recruitment in future
• “It’s nice to have somebody to talk it through with...” (Patient)

• “She was very helpful, she put my mind at rest, she answered questions that I hadn’t thought about, you know, and she gave me more confidence to be able to deal with what I’m doing” (Carer)

• “To me she was like the missing link that could explain everything to everybody and certainly was a great support to [patient] and his family” (Social Worker)

• “[Study Nurse]’s name appears in the notes on 6 different dates, referring to discussions I had with her to do with symptom management or arranging admission” (GP)
References


• Kimbell B, Murray SA. What is the patient experience in advanced liver disease? A scoping review of the literature. BMJ Supportive & Palliative Care 2013;Published Online First: 2 July 2013. doi:10.1136/bmjspcare-2012-000435.


